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ABSTRACT

This guide is aimed at improving health services for people with developmental disabilities by educating people presently training as health practitioners and persons working in community service programs. It contains information on health care needs of people with developmental disabilities and recommendations for health care practices adapted from accepted standards of health care for the general population. The guide covers definitions, health care services delivery trends and issues, general child and adolescent health care, adult health care, nutrition, reproductive health care and sexuality, dental health care, infectious disease, and chronic health conditions. Appendices provide immunization recommendations, client education information on identifying and managing minor illnesses, a list of 27 selected readings and educational materials, and a list of 26 Minnesota organizations and programs. (JDD)

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Quality Health Care

For people with developmental disabilities

A GUIDE FOR HEALTH PROFESSIONALS

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Photography by Christine Stehly

Preface

Every community resource that meets basic life needs, promotes good health, and remediates health problems, should be equally accessible to individuals with and without developmental disabilities. Though the situation has continually improved in recent years, many people with disabilities still have difficulty obtaining the quality health care they need and deserve.

In response to this need, the Minnesota Governor's Planning Council on Developmental Disabilities provided funding for creation of the Health Care Standards Project for People with Developmental Disabilities. The project — conducted jointly by Gillette Children's Hospital in St. Paul and the Minnesota University Affiliated Program on Developmental Disabilities at the University of Minnesota — has produced two booklets aimed at improving the quality and availability of health care for persons with developmental disabilities. The first booklet, *Quality Health Care for People with Developmental Disabilities: A Guide for Parents and Other Caregivers,* was designed to aid parents, advocates, helpers, coworkers, and friends as they assist individuals with disabilities to obtain health care and maintain a healthy lifestyle. This second booklet, *Quality Health Care for People with Developmental Disabilities: A Guide for Health Professionals,* is aimed at improving health services by educating people presently training as health practitioners and persons working in community service programs.

The content of this booklet provides the basis for appropriate, comprehensive health care that should be reasonably expected for people with developmental disabilities in all communities. This publication contains information on health care needs of people with developmental disabilities and recommendations for health care practices adapted from accepted standards of health care for the general population.

Provision of quality health care for individuals with developmental disabilities is an important and complex issue. This booklet is only one step toward reaching the goal of equal access to the best possible health care for all members of our communities.

Richard A. Nelson
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photo by Gregg Waterman

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I. Introduction

During the past 20 years, the United States has witnessed substantial changes in the scope and nature of services to people with developmental disabilities. These important changes in philosophy and practice are mirrored in the recently passed Developmental Disabilities Assistance and Bill of Rights Acts. This legislation sets forth national goals for improving the lives of people in our society with developmental disabilities. At the forefront of our national agenda is a commitment to promote the independence, productivity and community integration of people with developmental disabilities.

The priorities of this Developmental Disabilities Act are also reflected in recent changes that have occurred in the provision of services to people with developmental disabilities in Minnesota, and in other states throughout the United States. These changes in services increasingly emphasize the development of living arrangements, employment opportunities, leisure-recreation activities, and learning and training experiences in regular community settings. Because of new attitudes and service strategies, literally hundreds of thousands of people with developmental and related disabilities now enjoy the benefits of community living.

With any significant change there are always a number of unintended complications, as well as benefits. One serious challenge faced by consumers, policy makers, and service providers is the provision and effective coordination of community health services for people with developmental disabilities. As people with developmental disabilities increasingly turn to community-based services for their health care, those services must expand their expertise and adapt their service approaches in ways that enable them to offer appropriate care that meets the needs of those new consumers.

To prepare themselves to meet that challenge, health professionals can familiarize themselves with the characteristics of developmental disabilities, with health care needs of this population, and with the applications of general health care standards to those with disabilities. This guide offers people who are training for health professions, and personnel in community service programs, a resource for beginning that preparation.

Definitions

The term "**developmental disability**" gained widespread use with the enactment of the federal Developmental Disabilities Act in 1970. The Act applies the term to specific recipients of the legislation's funding, support and advocacy. A developmental disability is defined as:

> "Physical and/or mental impairment that is manifested before age 22, is likely to continue indefinitely, and will result in substantial functional limitation in several major life activities (e.g., self-care, receptive and expressive language, learning, mobility and independent living), reflecting the need for lifelong services."

By intent the definition does not contain specific medical diagnoses, but refers to the FUNCTIONAL status of the individual. There are no uniform medical consequences of having a developmental disability. The individual's health care needs may be as unique as those of any other person.

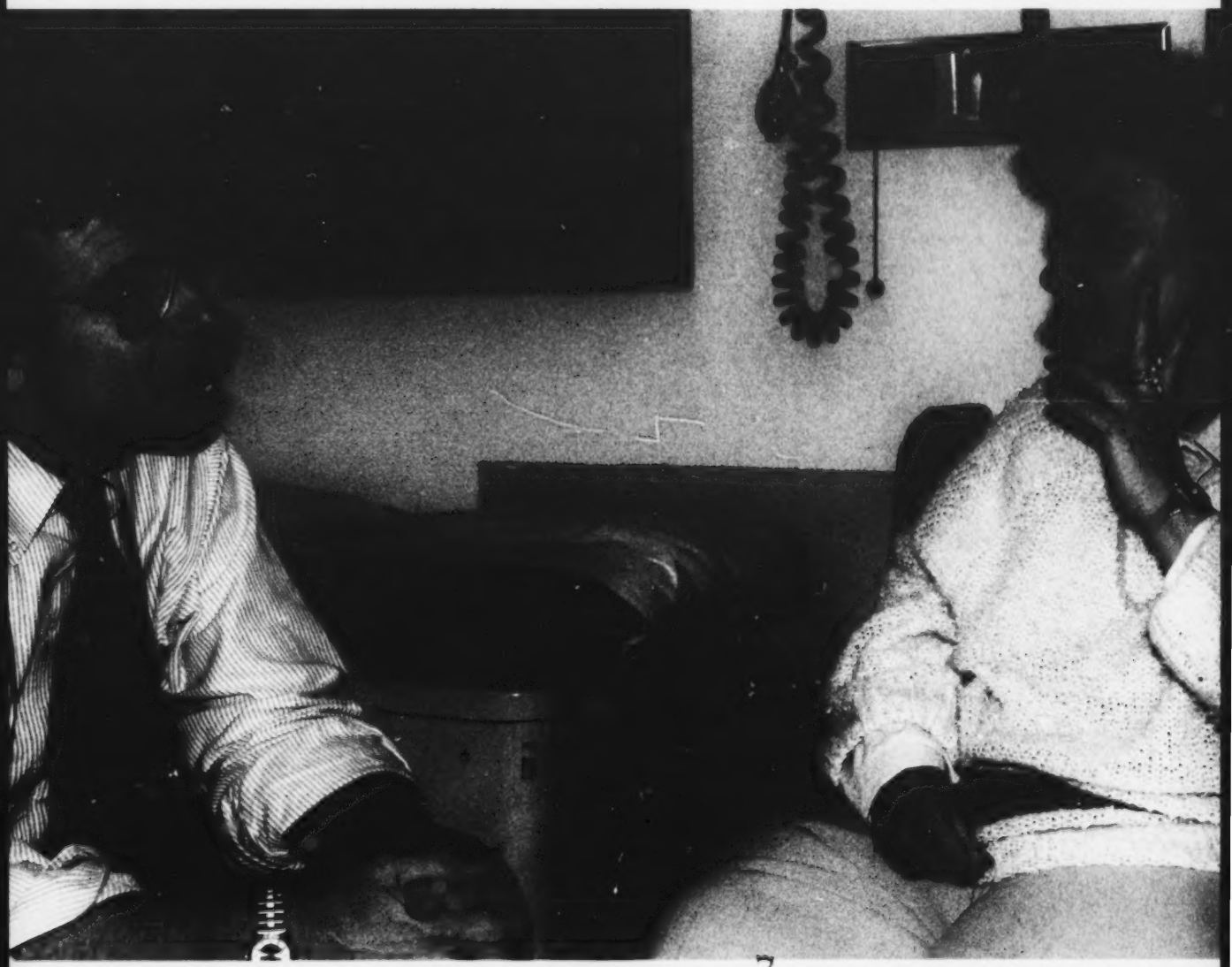
Within this broad category, clinical practitioners commonly see such conditions as autism, cerebral palsy, epilepsy, spina bifida, Tourette's syndrome, and mental retardation.

Autism is a condition of children, youth and adults that results in major disturbances of communication, socialization and learning. Autism can occur without any known associated metabolic or pathologic entity affecting the central nervous system. Observed abnormalities include delay, arrest or regression in developmental rates; atypical responses to sensory

stimuli; absent or limited verbal communication; and incapacity to appropriately relate to people, events or objects. The condition has a prevalence of about 5 per 10,000 and occurs more commonly in males. Intellectual development varies, but most individuals function in the subnormal range of mental ability.

Cerebral palsy is a non-progressive disorder of motion and posture due to brain insult or injury during the period of early brain growth. There is no single pathological etiology for this condition, and the majority of individuals probably have had a prenatal insult to the integrity of the central nervous system. Cerebral palsy can also result from such perinatal events as prematurity, asphyxia and intracranial hemorrhage. After the neonatal period, cerebral palsy can result from meningitis or head trauma. Characteristics of cerebral palsy include spasticity, hypotonia, abnormal motor movements and orthopedic deformity, occurring as individual deficits or in combination. The condition has a prevalence of approximately 1 per 1000. Commonly associated conditions include epilepsy, learning disability or mental retardation, and strabismus. The extent of dysfunction is highly variable.

Epilepsy is a condition of the central nervous system in which abnormal episodes of consciousness disturbance or involuntary motor movements occur. These episodes, generally called seizures, vary in frequency, clinical manifestations and severity. There is no single etiology. In the majority of individuals with recurrent or chronic seizures, the cause is unknown. In other situations, head trauma, intracranial infection or metabolic disturbance may have preceded the onset of seizures. Epilepsy is not invariably associated with



any intellectual deficit. About 1 in 100 individuals have a history of seizures. Modern anticonvulsant medications can effectively manage and control seizures for most individuals with epilepsy.

Meningomyelocele (spina bifida) is a congenital defect in the closure of the spinal canal with a hernial protrusion of the meningeal sheath of the spinal cord. The cause is unknown, although the interaction of multiple genes (polygenetic expression) and such prenatal environmental factors as maternal malnutrition and exposure to certain chemicals appear important. The overall incidence is estimated to be 1 per 1,000.

Individuals with meningomyelocele may have several associated problems that include hydrocephalus, vertebral and spinal column malformations such as kyphosis or scoliosis, loss of sensation and motor function to lower extremities, and urinary tract and bowel dysfunction. The number and extent of these problems is related to the location and size of the spinal cord lesion. Many people with meningomyelocele require services from multiple specialists and their health care requires careful coordination.

Tourette's syndrome is patterned involuntary movement of muscles or muscle groups that includes both motor and vocal tics. There are no definitive data, but estimates of prevalence range from .1 to 1.6 per 1,000. The age of onset is from 2 to 15 years of age. A multifactorial etiology is suspected including genetic and biochemical factors. Recent studies show an association between obsessive-compulsive behavior, attention deficit disorders, and Tourette's syndrome.

Mental retardation is the most common developmental disability and occurs in about 2 out of 100 people. There is no single cause of mental retardation. The term refers to significantly subaverage general intellectual function and adaptive behavior manifested during the developmental period (childhood and adolescence). Adaptive behavior is the degree to which an individual meets standards of personal independence and social responsibility for his or her age and cultural group. Both intellectual functioning and adaptive behavior should be assessed using standardized measures. When the level of intellectual functioning is greater than two standard deviations below the mean achieved by a peer group AND there are significant adaptive behavior deficits, a person is often defined as having mental retardation.

Other related conditions can create the same compromises or special needs for individuals as the preceding diagnostic conditions. These conditions include sensory deficits accompanied by learning or physical limitations, multiple physical abnormalities, or disorders of cognitive function. How well an individual functions determines the impact of a developmental disability on daily living.

Official definitions of "developmental disabilities" are important to use in determining eligibility for services covered by the federal Developmental Disabilities Act and various state statutes. In addition, a specific diagnosis within this generic category is necessary for planning and providing services. It is important, however, to think of people with developmental disabilities, first and foremost, as people with ability. While they require some degree of special assistance to take advantage of our society's freedoms and opportunities, they are fundamentally more similar to the rest of the population than different.

Current Service DeliveryTrends*

A 1987 monograph published by the Minnesota Governor's Planning Council on Developmental Disabilities entitled *A New Way of Thinking* describes fundamental changes in the way our society perceives people with disabilities and concomitant changes in service delivery and organization for these individuals. These changes have important implications for health services delivery as well, and several will be highlighted.

A new way of living: "There is a growing recognition that having a real home is as important for people with developmental disabilities as it is for everyone else" (p. 22). This recognition has led to significant shifts in residential services, known as DEINSTITUTIONALIZATION. This trend is characterized by efforts to reduce the number of people in regional treatment centers and to increase community living options. Resources include support for families so that individuals with developmental disabilities can live with

*The material in the next two sections is adapted from a report published by the Minnesota Governor's Planning Council on Developmental Disabilities, A New Way of Thinking (1987), and the reader is encouraged to obtain a copy of this publication for a complete discussion of these issues. They are also portrayed in an award winning video production of the same title. Full citations and information on how to obtain these and other resources are listed in Appendix C.

their own families or foster families, supported independent living arrangements, or semi-independent living arrangements in small group homes. Although further progress is needed toward the goal of community living, many people once institutionalized now live in home communities and seek health care in these communities as well.

A new way of learning: "When the institutional approach prevailed, young people with developmental disabilities did not attend public schools; they stayed at home, were admitted to state institutions, or attended special, private schools" (p. 10). A shift begun in the late 1950s directs all children toward regular, public schools. The Education for All Handicapped Children Act (P.L. 94-142), passed by the federal government in 1975, mandates free and appropriate education in the least restrictive environment. This movement to include children with disabilities in their local neighborhood schools and provide education in regular class settings is known as INCLUSIVE EDUCATION. The act also requires an individual education plan (IEP), developed by parents and an interdisciplinary team.

In 1987, the Education for All Handicapped Children Act was amended to include early intervention for infants and young children. The new act (P.L. 99-457) also mandates a family-oriented plan or individual family service plan (IFSP). Infants and young children with complicated health service needs necessitate that health providers work closely with the family and other service providers to develop a comprehensive and coordinated service plan.

Health Care Sevices Delivery Issues

Individuals with developmental disabilities have the same basic health care needs as the general population. As a group, however, they have a high incidence of health problems and disabilities which, if left untreated, could significantly decrease their potential for development and adjustment.

The extent of health services needed varies with each individual. For example, young children with developmental disabilities always require a thorough evaluation, and many will need specialized diagnostic and rehabilitative services. This early intervention is critical for reducing adverse long-term effects of numerous conditions.

Health care for people with developmental disabilities typically requires the cooperative efforts of multiple professionals and agencies. The participation in care or services by an increased number of providers contributes to the frequency or complexity of treatment. It also challenges providers to maintain a coordinated care plan with consensus about treatment goals. Family members should be consulted and encouraged to actively participate in decisions regarding care. It is important to carefully coordinate specialized care with routine preventive health care. In some situations, a case coordinator may be needed to ensure services are appropriately arranged for and received by the individual.

A person with a developmental disabilities who also has an emotional or behavioral disorder presents a major challenge to the physician or therapist. Positive approaches to behavioral management are preferred, but must be adapted to the person's level of cognitive function. Excessive and often inappropriate use of medications to manage behavior disorders is a frequent concern in service programs. Psychoactive medications, if used, must be prescribed and managed in the context of a comprehensive treatment program that provides support for usual daily activities. University centers or specialized

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Dan Romero* uses a wheelchair, although with help he can stand and walk a few steps. The first time Dan had a physical with his new doctor, the physician never had Dan get out of the chair. She assumed Dan couldn't get up, and Dan felt too intimidated to suggest the doctor do the exam differently.

If the doctor had only asked Dan or his family, her patient could have received a more comprehensive and complete physical.

*Not real name

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clinics may offer specific management suggestions and follow-along care.

People with developmental disabilities may experience barriers to receiving quality health care. The frequency and extent of these impediments are related to the availability of and access to services. Medical and other health care specialists do not practice in all communities — especially in rural areas. Special transportation arrangements may be necessary. Inadequate medical supplies, funding of care, and durable equipment may also limit treatment options.

Physical accessibility of offices and other health facilities is a basic consideration that is sometimes overlooked. In addition to entrances that accommodate wheelchairs and other mobility aids, and elevators in buildings with more than one level, consideration should be given to accessible and conveniently placed rest rooms and water fountains, adjustable exam tables and other equipment that can be positioned to facilitate exams and procedures for individuals with mobility impairments. It is also important that staff be trained to lift and position clients properly when this type of assistance is required.

Although most developmental disabilities are static conditions, some individuals experience increasing functional disabilities as they grow older. They may also acquire unrelated chronic diseases that compromise function. Individuals with conditions such as muscular dystrophy, tuberous sclerosis, neurofibromatosis and progressive metabolic disorders will experience distinct loss of function that requires increased care over time. In these situations, providers must be alert to the changes in the individual's physical and functional status. Health care requirements and all aspects of daily living should be carefully evaluated so that needs continue to be met. Major interventions, including new programs or intensive medical treatment, should be planned through an interdisciplinary process involving key providers, extended family or a client advocate, and the affected person whenever possible.

If the condition is progressive and death may be likely, the extent of life support should be discussed with all concerned parties. There should be every attempt to resuscitate an individual after respiratory or cardiac arrest unless another decision previously has been made. A deliberate decision should be reached through an appropriate process prior to such a catastrophic event.

II. General Child and Adolescent Health Care

A child in good health has the potential for optimal physical, intellectual and emotional growth and development. In addition, a child's chances for becoming a functional and productive adult are enhanced when health is optimal throughout the developmental period. There is no other period in the life span where the rewards of health supervision and preventive care are as great.

Health Supervision

Every child should receive regular health, growth and developmental assessments by trained health professionals. The American Academy of Pediatrics suggests the following schedule for health supervision visits, and notes that some children require more and others less care depending on individual health needs or conditions. These guidelines are the best current estimates of average needed services.

- **Birth and during acute illness:** Health supervision visits should occur at birth and during acute illnesses.
- **Infancy period (up to 2 years):** Health supervision visits should be made at least five times during the first year and three times during the second year.
- **Preschool period (2 to 6 years):** Health supervision visits should be made at least three times during this period, at about 2 years of age, 3 years of age, and again at 5 to 6 years.
- **School age (6 to 18 years):** Health supervision visits should be made at least four times during this age span.

Health supervision is more than a "well child" visit. Supervision provides:

- Diagnosis and treatment of minor illness and conditions that families "save up" for routine health visits.
- Early diagnosis and treatment of illness and conditions not obvious to family members.
- Assessment and management of chronic conditions.
- Counseling for the child and family regarding such topics as development, nutrition and injury prevention.

Health supervision visits should include the following activities:

- Review and discussion of the child's health and developmental history since the last visit.
- A complete examine of the child. Record any variations from normal.
- Recommended immunizations. (See Appendix A)
- Frank discussion of the child's physical, mental, and behavioral status and problems. Based upon the results of the examination or concerns raised by the child and/or parent or guardian, a variety of subjects may arise that will need discussion and counseling.
- Written instructions concerning the child's specific needs, including information to promote health such as dietary recommendations and treatment recommendations for any special health problems.

Adolescent Health

Adolescence is characterized by rapid physiological and psychological change. Health professionals must have the knowledge and technical skills required to manage concerns relating to sexuality, family and peer relationships, risk-taking behaviors and self-image.

Adolescents with disabilities are an especially vulnerable group because their disabilities are compounded by the biological and psychological changes of puberty. Many chronic health conditions impose activity and/or dietary restrictions inconsistent with the adolescent need for autonomy or desire to be like peers. Other conditions may impede the development of satisfactory self-image or self-esteem.

Adolescents with disabilities and their families are likely to have multiple needs. The services of professionals in such disciplines as nursing, psychology, social work, family counseling, and medicine are recommended.

To provide meaningful and comprehensive health care to adolescents, the health assessment must determine the:

- Stage of physical development.
- State of psychosocial development and function.
- Presence of abnormalities requiring treatment.
- Presence of risk factors for future disease.
- Existence of minor problems that may have major meaning to the adolescent.
- Consequences of the adolescent's lifestyle and environment.
- Health knowledge, behavior, and educational needs of the adolescent.

Special Issues for Children and Youth with Disabilities

Children and youth with developmental disabilities may or may not have special physical health care needs. In uncomplicated mental retardation or autism, for example, the health status of the individual may be unremarkable. In these situations, the health care practitioner should follow standards and guidelines proposed for the general population. Most individuals with developmental disabilities, however, will need some adaptation in health services to accommodate the particular nature of their functional limitations.

Some children with atypical development or behavior may be difficult to examine due to inattention, oppositional reactions, or apprehension, and, in some cases, physical deformity. These difficulties may be compounded when a non-verbal child or youth cannot provide information about symptoms of an acute illness. Physicians and other practitioners generally find that a thorough interview with the parent or primary caregiver provides an adequate history of illness. A relaxed, minimally threatening physical examination then provides necessary diagnostic information. It is important to know the child or youth's approximate level of intellectual functioning so that there is neither an underestimate or overestimate of the child's understanding. The professional may ask the family to prepare the child by explaining and/or demonstrating the exam before the appointment. Professionals should discuss with the family the preferred way to address, approach and communicate with the child to reduce anxiety.

Children and youth with multiple disabilities present a special challenge. Their health conditions often require sophisticated medical technology for diagnosis and management. They may require the services of a team of health providers, including several specialists.

Health providers need to recognize how a chronic illness, in addition to a developmental disability, affects growth and development.

Finally, there is a need to understand the stresses with which families must cope. Complex care regimens place special demands on families and caretakers, and the high cost of this specialized care can be a financial burden. Health care providers must carefully assess family functioning, keeping demands of care within a tolerable range while supporting individual and family autonomy.

III. Adult Health Care

Adult health needs are less predictable than a child's and there is no uniform agreement on intervals between exams. The frequency of health visits should be determined by individuals needs. Similarly, the content and focus of health care depends on the person's age and specific concerns.

Regardless of age, evaluation of the adult follows the same series of steps:

- Collect data from the history, the physical examination and the laboratory.
- Organize and synthesize the data to produce a list of problems or diagnoses that determine the need for the further evaluation or suggest initiation of specific therapy.
- Review efficacy of therapy and validity of diagnosis over time.
- Collect further data as needed as new problems or diagnoses arise.

Adults should receive routine preventive health services that are comprised of the following components:

- Periodic preventive health services, including history (medical, social and occupational history and lifestyle inventory), physical examination, and laboratory tests appropriate to age and health risks. The examination should include blood pressure measurement and management when abnormal; simple screening for visual and auditory acuity and dental status, with referral or treatment of abnormalities; glaucoma screening for individuals at risk; cancer screening at appropriate ages such as inspection of skin, examination of the stool for occult blood, breast examination and pap smears for women, mammography for those woman over 40 and testicular exam for men; and cholesterol screening.
- Nutritional assessment.
- Patient education on such topics as breast self-examination, testicular self-exam, nutrition, exercise, accident prevention, and substance abuse (alcohol, tobacco, and drugs).
- Psychosocial needs assessment, with referral when indicated, to social and mental health services.
- Contraceptive information and services when appropriate.

IV. Nutrition

The body metabolizes nutrients for tissue formation, growth, repair and maintenance. These nutrients are carbohydrates, proteins, fats, vitamins, minerals and water. In total, 40 known nutrients play an essential metabolic role.

Nutritional requirements vary during the life cycle. The needs are greatest during periods of rapid growth and decrease as growth slows or ceases. Periods of peak nutritional needs come between birth and 2 years of age and at adolescence. Direct careful attention to these growth periods to assure adequate nutrients and energy to promote optimal growth, development, and health.

The nutritional needs of people with disabilities have not been shown to be different from typical population groups with regard to the Food and Nutrition Board's Recommended Dietary Allowances. However, people with developmental disabilities are at a higher risk for nutritional problems due to a high incidence of eating disorders and their frequent reliance on others for food selection, preparation and availability.

People with developmental disabilities require basic nutritional screening and assessment, preventive services, treatment for identified conditions, and follow-up services in orders to receive appropriate health care.

Atypical Feeding Capability or Eating Behaviors

Individuals with physical disability involving oral-motor dysfunction are at higher risk for inadequate intake. Uncoordinated sucking and/or swallowing is frequently observed in neurologically compromised infants. Other young children may consume fluids relatively well, but be unable to chew or swallow solid foods. The converse may also be true.

Swallowing may be complicated by aspiration of foods or fluids into the lungs, or reflux of stomach contents up the esophagus with resulting vomiting or aspiration.

Parents or caregivers may not detect mild abnormalities in feeding capability. In these situations, careful monitoring of weight (and body length in a child) and physical examination may be required to detect nutritional deficiency.

Abnormal eating behaviors are observed in greater frequency in people with developmental disabilities than in the general population. Clinical problems such as hyperactivity, anorexia, rumination or recurrent vomiting may be associated with poor growth and weight loss in the absence of any anatomical or biochemical defect. One should carefully evaluate these conditions to determine if any specific environmental factors induce or aggravate the undesirable behavior. Environmental control, including careful planning of the diet and meal supervision, is often the most appropriate management strategy.

Altered Route of Feeding (Gastrostomy)

Some children and adults require an alternative feeding method due to inadequate caloric intake or recurrent aspiration. An infant whose eventual feeding capability is unknown may require a feeding tube through the nose or mouth into the stomach to deliver formula. If the feeding deficit appears to be indefinite, a "permanent" gastrostomy may be surgically inserted through the abdominal wall. Subsequent management of feeding should be under the direction of a physician and nutritionist. Some individuals, especially those with progressive muscular dysfunction, might do well with night-time continuous drip nasogastric feedings, which frees them and their caregivers to use waking hours for other activities.

photo by Cheri Gilman

Abnormal Patterns of Elimination (Constipation)

Inactive or immobile individuals and people with neuromotor difficulties can have a decreased frequency of bowel elimination. Poor fluid intake and a diet deficient in bulk or fiber will also contribute to constipation, a common occurrence in people with neuromotor difficulties. Diet modification is generally the first approach to managing constipation. Medicinal stool softeners or laxatives also may be necessary.

Varying Caloric Requirements by Disability

Age, body size and energy expenditure determine daily caloric requirements. Relatively inactive people may need fewer calories whereas the opposite is true for very active individuals. There is no precise clinical method for calculating the caloric requirements of an individual with a specific disability other than through serial weight measurements and dietary analysis.

Other Factors Affecting Nutrition

Food choice and preparation is determined by several factors. Most people make food choices based upon their eating habits and preferences, and on food costs. Limited income, poor food selection habits, and a lack of cooking skills can contribute to poor nutrition. These characteristics may be special problems for individuals with disabilities who live independently. Nutritional education and reinforcement of healthy practices are essential in these circumstances.

V. Reproductive Health Care and Sexuality

Reproductive health services should be an integral part of the comprehensive health services provided for both males and females. The examining physician or nurse practitioner should provide a full range of reproductive health care, including information and education about health maintenance, developing and changing sexuality, contraception, genetic risks of reproduction, and specific medical and surgical conditions related to gynecology. Health practitioners should teach breast self-examination to women, and testicular self-examination to men. In addition, practitioners should make each woman and man aware of common sex-related health risks for various times of their lives.

Overall health care should include a recognition of sexual, psychological and social needs. The practitioner should identify areas of difficulty and, when necessary, involve available community services for patient and family support, such as sexuality education and contraceptive services.

Gynecological Health

Women should have a gynecologic examination at least by age 18, and routinely thereafter. Sexually active women should have periodic examinations regardless of their age. The frequency of such an examination depends on the woman's lifestyle and the risk of disease at various times of her life.

Women should be adequately prepared for gynecological exams. Such preparation might include a description of the procedures using pictures and/or models, and relaxation techniques. For some women with developmental disabilities, a thorough gynecological exam may take extra time. A longer appointment may be necessary to accommodate special needs.

Sexuality

Unless there is contradictory evidence, one should assume that sexual function (including sexual intercourse and masturbation) and reproductive capability (fertility) are normal regardless of mental age or physical disability. Some individuals with disabilities have delayed onset of puberty which may reflect inadequate gonadal function. When appropriate, an endocrinological evaluation should be undertaken if there is a suspected clinical problem.

During recent years there has been considerable emphasis on providing adequate sexuality education within the scope of a person's understanding in order to encourage good personal hygiene, appropriate behavior in individual and congregate settings, and to limit sexual vulnerability.

Reproduction and Contraception

Adolescents and adults with mental retardation have several special reproductive concerns. In any circumstance when a person with mental retardation lacks the knowledge or judgement to make personal decisions regarding reproductive care, there is a need for personal advocacy on his or her behalf. Parents often provide that advocacy for minors. When the person reaches adulthood, the parent may obtain permission to continue in that role. The competence of the young person to make independent decisions may involve a determination by a court of law.

Comprehensive health care should include contraceptive services. Men and women should receive education, counseling, and referral to screen, detect, prevent or treat a variety of conditions with the objective of achieving and maintaining a state of good reproductive health. All people desiring contraceptive advice or techniques should be given information, methods or medication consistent with sound medical judgment and compatible with their personal convictions and capabilities.

These reproductive health services have two important functions: 1) to identify by history or examination, factors that affect or limit contraceptive choices, and 2) to provide preventive health screening and counseling.

Woman using hormonal contraceptives and intrauterine

devices (IUDs) are at higher risk for certain complications, and complete annual examinations are recommended. Healthy women using other methods of contraception require less frequent evaluations. Whenever sterilization is considered, the guardian or conservator must generally obtain court permission to perform the medical procedure. Surgical sterilization is considered an irreversible procedure regardless of whether the operation is performed in a man (vasectomy) or woman (tubal ligation).

The availability of medical contraception, and the recognition that training and appropriate supervision can provide satisfactory menstrual care in almost all situations has eliminated hysterectomy as a procedure for either contraception or menstrual hygiene.

Obstetrical Health

Every woman should have a comprehensive program of obstetric care that begins as early as possible in the first trimester of pregnancy (preferably before conception, when pregnancy is anticipated), and extends through the postpartum period. Early diagnosis of pregnancy and risk assessment are important to establish the appropriate management plan. Consideration of each woman's special needs—medical, emotional and educational—helps promote quality obstetric care.

A comprehensive range of obstetric health services should be offered. These services include medical, nursing and social work care, as well as nutrition and general health education. When primary providers are unable to offer comprehensive services, they should make appropriate referrals to community resources.

When an unwanted pregnancy occurs in a woman with mental retardation, health care providers should follow established guidelines. If the court previously has found a woman to be incompetent for her own care and she has a guardian or conservator, the court would likely find the woman unable to adequately care for a child. In circumstances where the competency of the woman to parent is less clear, and especially when the woman expresses her desire to carry the pregnancy forward and parent the child, social and public health nursing services should provide very close family supervision to assure that the needs of the woman and child are appropriately met.

A pediatric nurse practitioner provided primary care to Karen Krause, a girl with developmental disabilities, since shortly after Karen's birth. When Karen — now a young woman — requested a pregnancy test, the nurse practitioner was shocked. She had failed to notice that Karen, who had cerebral palsy and mild mental retardation, had grown up.

Because of the young woman's disabilities, the nurse practitioner unconsciously thought of Karen as a child who was neither emotionally or physically capable of becoming sexually active.

*Not real name.

Sexual Vulnerability and Safety

Individuals with disabilities may be more vulnerable to unwanted sexual advances or attacks. Some may have difficulty distinguishing inappropriate behavior, while other individuals may be physically vulnerable. In addition, offenders may think a person with a disability is less able to report or talk about an assault.

Periodic individual and peer-group education, as well as monitoring are necessary to reduce this vulnerability. Health providers should also encourage frank discussions about sexual vulnerability and safety with clients and their parents or caregivers. Aspects of the physical exam may include touch that is confusing to some clients. It may be necessary to help them distinguish what may be appropriate in that context that would not be in others.

Finally, service providers should be alert to any indications of sexual abuse. As with physical abuse, professionals are required to report suspected sexual abuse of a child or vulnerable adult to local protection or law enforcement agencies.

FORCED OR
KISSING

VI. Dental Health Care

Dental health needs of people with developmental disabilities require special attention and related adjustments.

Satisfactory oral hygiene has been neglected in many people with disabilities. For some, physical limitations may make self-care difficult. Some children and youth are tactually sensitive and without persistent training there is a strong disincentive to brushing. Others may not be motivated to maintain adequate oral hygiene. In addition, limited funding of dental care and services in many communities may present problems.

All programs that serve children, youth and adults with disabilities should have a dental health component. Promoting oral health through outreach, assessment, dental health education and preventive services should be a priority to minimize remedial care and to maintain satisfactory oral function. Every person should have a source of ongoing dental care.

As primary care providers, dental personnel should be fully cognizant of each patient's medical, physical and emotional condition. The patient with a disability may have a variety of factors to consider in planning dental care. The "modifications" needed to treat a dental patient with developmental disabilities are quite often no more than a thorough patient assessment, with extra time to perform clinical procedures. In addition, home care recommendations and expectation may need to be adjusted to levels realistic for the individual's condition and capabilities. For instance, a tooth brush may need to be modified to make it easier to grasp.

Although many dentists treat people with developmental disabilities, pediatric dentistry is a dental specialty that specifically includes the treatment of people with disabilities. By definition, pediatric dentistry includes the care of special patients beyond the age of adolescence who have mental, physical, and/or emotional problems as well as the care of children. Health professionals and clients seeking a dentist who is prepared to treat people with developmental disabilities can call their local dental society.

Treatment Planning

To formulate a treatment plan, clinical data from a thorough extraoral and intraoral examination, dental charting, periodontal charting, orthodontic assessment and radiographic survey is needed.

To accurately integrate preventive services (scaling, polishing, fluoride use, plaque control, nutritional counseling and/or placement of sealants) into the treatment plan, practitioners should be aware of any limitations a patient's disability may place on the ability to receive treatment.

While most routine procedures and education remain the same as for patients without disabilities, special consideration should be given to any cognitive or sensory difficulties that the disability creates, and appropriate adjustments made to accommodate the understanding of the patient. This may include demonstrations with models or illustrations, or allowing extra time to explain procedures.

Examinating Uncooperative or Frightened Patients

Dental hygienists and dentists frequently cite difficulties in examining uncooperative or frightened patients as the primary barrier to serving people with developmental disabilities. While reassurance, patience and painless technique can often alleviate anxiety, some situations may require some degree of sedation. It's possible that dental treatment may require general anesthesia that necessitates specialized out-patient or inpatient facilities. While routine physical restraint is NOT recommended, some patients may need to have a stabilizing restraint to limit movement during dental procedures. These may include hyperkinetic patients, or those with spastic or athetoid cerebral palsy.

Prosthodontic Care

In the past, social and dental practice relied more frequently on removal rather than definitive restorative care. Therefore, a significant number of older people with developmental disabilities are completely or partially edentulous. Some individuals have arbitrarily been judged unable to use dentures and related appliances, and these devices have not been prescribed.

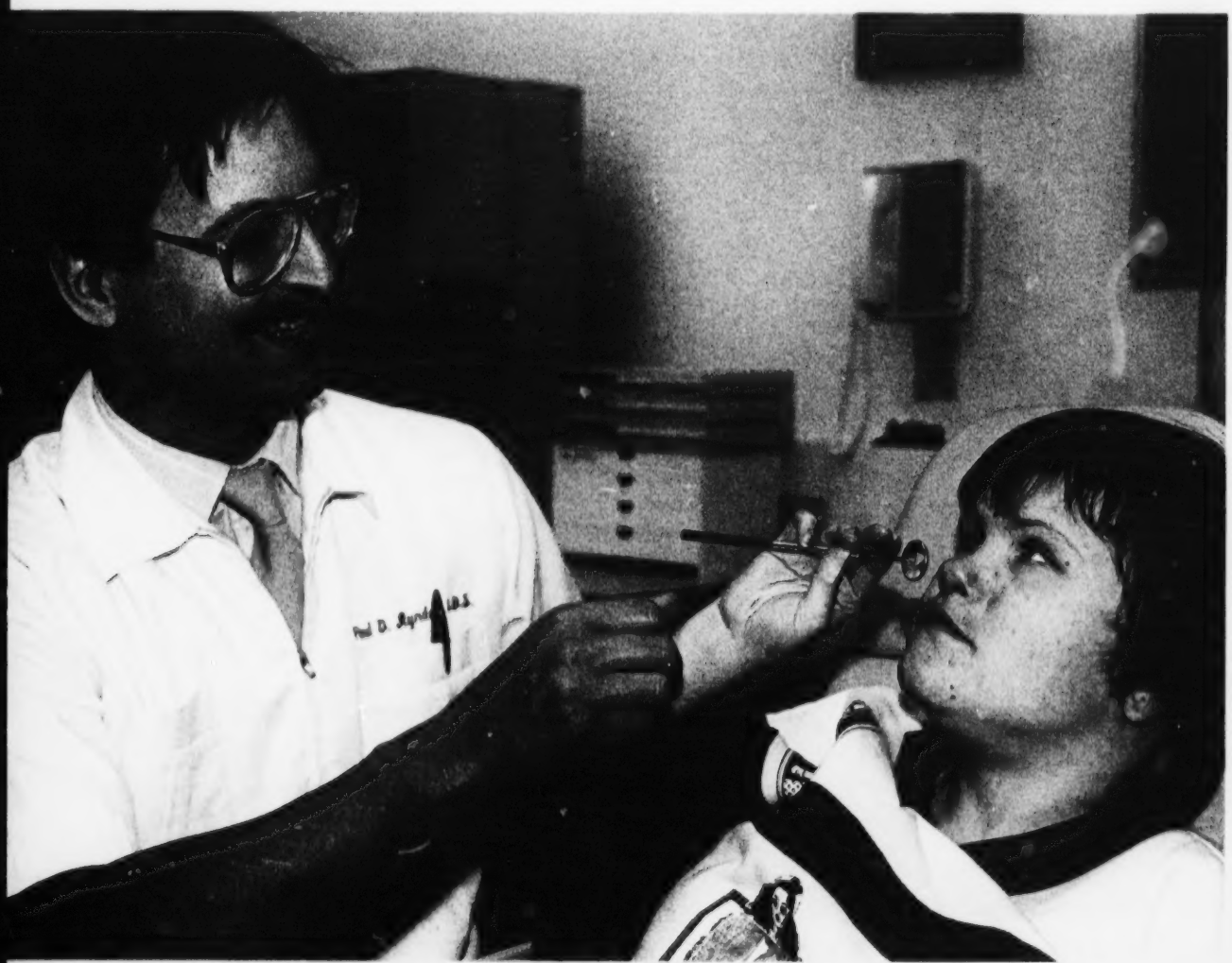
It is now recognized that dentures may be appropriately worn by many adults with mental retardation and other disabilities in order to promote a normal diet and facilitate intelligibility of speech. All edentulous individuals should be evaluated for the potential use of dentures. Special attention should be given to educating patients and caregivers on proper use of dentures and related appliances.

Orthodontic Treatment

Orthodontic treatment is generally indicated when some significant functional improvement will occur as a result of treatment. Successful orthodontic treatment necessitates adequate oral hygiene during the treatment period. In severe cases orthodontic treatment and oral surgery may be necessary to correct a malocclusion or other deformity.

Infection Control Practices for Dentistry

Infection control practices are an essential element of dental health care provision. Due to the nature of many dental procedures, the risk of transmission of infectious disease is possible if precautions are not taken. Readers desiring more information on infectious disease control should consult The Centers for Disease Control recommendations (1986).



VII. Infectious Disease

Recommended Immunizations

The most commonly recommended immunizations include: diphtheria-tetanus-pertussis (DTP), polio, measles, mumps, and rubella. Appendix A presents a normal schedule of immunizations for children, as well as recommendations for adult immunization. Several factors that influence recommendations concerning vaccine administration include age-specific risks of disease, age-specific risks of complications, ability of individuals of a given age to respond to the vaccine(s), and potential interference with the immune response by passively transferred maternal antibody.

Hepatitis B Virus (HRV)

The onset of acute hepatitis B is generally insidious. Clinical symptoms and signs include various combinations of anorexia, malaise, nausea, vomiting, abdominal pain, and jaundice. Skin rashes, arthralgia and arthritis can also occur. Overall fatality rates for reported cases generally do not exceed two percent. The incubation period of hepatitis B is long, generally 45-160 days (average 60-120).

It is not uncommon to find a higher percentage of group home residents to be chronic asymptomatic carriers of hepatitis B, although the rate varies among communities. If there have not been any recognized cases of hepatitis B within the last 10 years in a facility, there is probably no need to vaccinate staff or residents. If clinical hepatitis B is recognized, consider screening staff and residents and vaccinating those who are susceptible. In larger facilities, it is possible to separately evaluate units that care for more aggressive or self-injurious people and screen the staff and residents of those particular units for hepatitis B carrier status. With that knowledge, decisions can be made regarding the need for vaccination in individual units.

The risk of hepatitis B varies from one location to another. Check with your state or local health department for current recommendations for your area.

Tuberculosis

Tuberculosis remains a significant public health problem because of its communicability and serious health implications if left untreated. Due to the persistence of tuberculosis in the United States, it is recommended that all communities provide at least a minimum level of tuberculosis services. These services should include tuberculosis screening, contact investigation ,and home care visits for patients on medication. The use of these services in group living arrangements should be based on the prevalence of tuberculosis in the community and the diverse histories of residents.

Sexually Transmitted Diseases

Sexually transmitted diseases (STDs) vary in causative agent, symptomatology, and treatment. To reduce the risk of STDs, those who are sexually active should:

- Avoid multiple partners, anonymous partners, prostitutes and other people with multiple sex partners.
- Avoid sexual contact with people who have a genital discharge, genital warts, genital herpes lesions or other suspicious genital lesions.
- Avoid oral-anal sex to prevent enteric infections.
- Avoid genital contact with oral "cold sores."
- Use condoms and diaphragms in combination with spermicides.
- Have a periodic examination for sexually transmitted agents and syndromes if at high risk for STD.

Accurate identification and timely reporting of sexually transmitted diseases is an integral part of a successful disease control. All clinicians, health facilities and laboratories should report, within 48 hours, STD diagnoses and positive STD laboratory results to local or state health departments according to established policy.

Meg Anderson*, a woman with severe cerebral palsy, scheduled an appointment to see her family physician. After waiting more than 30 minutes in the reception area, she finally was ushered to the examining room. The doctor, who was seated at his desk, did not mask his irritation with his patient.

"Well Meg, why are you here?" He spoke slowly. "You have cerebral palsy, and you know we can't do anything about that."

"But doctor," she responded, "I have a terrible sore throat and an earache."

*Not real name.

Special Considerations for People with Developmental Disabilities

The recognition of infectious disease is dependent on the accurate assessment of signs and symptoms. Signs are physical changes that are observable by a person other than the ill individual. They include changes in skin color, rashes, swelling or differences in stamina and physical function.

Symptoms are the subjective feelings an ill person may have that are not obvious to the observer. Symptoms include pain, dizziness, mild weakness, or internal discomfort such as abdominal cramping. People with developmental disabilities, as well as family members or caregivers, should be taught to recognize changes that may signal the onset of an infectious disease. Health providers should emphasize the value of prompt evaluation and treatment. Discomfort, cost or complexity of care, as well as unfavorable outcomes, can be avoided by teaching clients the importance of prompt evaluation. Further information for client education is provided in Appendix B.

VIII. Chronic Health Conditions

In addition to medical treatment, comprehensive health care for children and adults with chronic illness or disability must include social, psychological, educational and vocational services as appropriate. Social and health services in rehabilitation and chronic care are inextricably related.

Early assessment of the clinical aspects, functional status and social components of each person's problem is an integral part of comprehensive health care. Failure to determine the causes and evaluate the effects of chronic illnesses and disabilities often results in recurring hospitalization, progressive deterioration of mind and body, and increasing dependence. The financial, emotional and social impact can be catastrophic, particularly in children for whom proper early assessment can affect the extent of disability, with all its consequences, for an entire lifetime.

Each person with chronic illness or disabilities should have access to programs designed to bring or restore the best physical, psychological, vocational and social functioning possible within the constraints imposed by the illness and social setting. Continuing programs should be available so that all gains can be sustained and extended.

Atherosclerotic Disease

The incidence of atherosclerotic cardiovascular disease reaches substantial proportions beyond age 45 in men and 55 in women. This class of disease constitutes the most frequent cause of short-stay hospitalizations, and the highest costs per admission. The chances of an American male developing some clinical manifestation of atherosclerotic cardiovascular disease before the age of 60 are still close to one in three.

Atherosclerosis development has been associated with various risk factors. Since risk factors are often multiple and clearly synergistic, a comprehensive strategy of intervention is mandatory and should address:

- Weight.
- Blood lipids.
- Hyperglycemia and diabetes mellitus.
- Hyperuricemia.
- Hypertension.
- Cigarette smoking.
- Physical activity.

Clinical presentations of chronic coronary heart disease may include angina pectoris, heart failure, dysrhythmia or systemic embolization. To reduce the risk of sudden, unexpected death and/or acute myocardial infarction, it is important to educate the public in detecting symptoms and signs and in modifying risk factors. Be aware that cigarette smoking, hypertension, hypercholesterolemia, severe obesity, diabetes mellitus, positive family history, and especially the presence of more than one of these risk factors, increases the risk of coronary artery disease.

Hypertension

Control of high blood pressure begins with detection and requires continued surveillance. Health care professionals are strongly encouraged to measure blood pressure at each patient visit. Individuals without regular contact with the medical care system should have their blood pressure measured at least once every two years.

Successful therapeutic intervention and follow-up begins with an assessment of patient readiness to control blood pressure and learn related behaviors. The patient's prior health practices and experiences with following health regimens should be considered along with physical, mental and emotional capacities to adjust to recommended changes.

Effective treatment of hypertension can be achieved through the use of antihypertensive drugs and/or nonpharmacologic approaches. Examples of the latter include:

- Reducing weight.
- Modifying sodium intake.
- Moderating alcohol consumption.
- Avoiding tobacco.
- Exercise.

Cancer

Cancer is the second leading cause of death for Americans, surpassed only by cardiovascular diseases. Early detection and preventive measures, sometimes successful in reducing the incidence and severity of cancer, include:

- Reducing and ultimately eliminating cigarette smoking.
- Including proctoscopic examinations in annual checkups for those over 50 years of age.
- Examining testicles as a monthly male practice.
- Examining breasts as a monthly female practice.
- Having mammograms for women 40 and older.
- Taking pap tests for all adult and high-risk women.
- Avoiding excessive sun.

Diabetes

Diabetes is a chronic health condition caused by lack of insulin or the inability of the body to use insulin.

The goals for management of patients with diabetes are: (1) improved treatment of diabetes to delay or prevent complications, (2) early detection of complications, and (3) prompt and appropriate treatment of complications once they have been recognized.

The most common complications of diabetes are visual impairment, adverse outcomes of pregnancy, foot problems, kidney failure, acute hyperglycemia with ketoacidosis, increased risk of hypertension and cardiovascular disease.

Hypoglycemia occurs when the rate of glucose entering the circulation does not keep pace with the utilization of glucose by the peripheral tissues. The most common causes of hypoglycemia are excessive insulin, inadequate food intake, sustained physical exertion, and drugs.

Adherence to the following guidelines will assist in preventing hypoglycemia:

- Ensure correct technique of insulin injection and rotation of sites.
- Adhere to regular mealtimes and snacks as recommended.
- Correctly interpret results of home blood glucose and urine tests.
- Substitute oral liquid containing carbohydrates when food intake is reduced due to illness.
- Eat a snack before engaging in some forms of exercise.
- Adjust insulin dosage only according to physician's guidelines.
- Give correct amount of insulin.

Epilepsy

Epilepsy is a condition when a person has had at least two seizures at separate times during a lifetime. Prompt diagnosis and treatment are essential for the person experiencing a first seizure. Although control of seizures is paramount in the treatment of epilepsy, it is only part of the treatment. The behavioral, social and economic consequences of uncontrolled seizures are enormous. Substantial amounts of emotional support involving a team of nurses, social workers, vocational counselors, and other health professionals are often necessary.

Rheumatic Disease

Rheumatic diseases fall into two broad categories: systemic rheumatic diseases and regional rheumatic diseases. Systemic diseases include rheumatoid arthritis, systemic lupus erythematosus, scleroderma and polymyositis. Those affected are chronically ill, have intermittent and remittent easy fatiguability, and often suffer stiffness and generalized weakness. Joint pain and deformity are often features of these diseases. But the cardinal feature is the pervasive sense of being sick for prolonged periods. These systemic rheumatic diseases affect approximately three percent of the population.

Conversely, people with regional rheumatic diseases are basically well. They suffer from pain and functional restriction in a single musculoskeletal region. Examples include low back pain, neck pain, tennis elbow, shoulder pain (i.e., "bursitis") and carpal tunnel syndrome. These illnesses, however, vary in intensity and tend to be self-limited. They usually remit, leaving some residual deficit. This form of arthritis may lead to a need for joint replacement, especially hip replacement.

IX. Additional Information

While the standards of health care and many of the health services are the same for people with disabilities as the general population, there may be some special issues to consider in tailoring services to individual needs. This publication is designed as an introduction to these standards and service needs. The reader is referred to the resources listed in Appendix C for more in-depth information on selected topics. Appendix D is a list of community resources for services providers and/or their clients.

photo by Gregg Waterman

X. Appendices

Appendix A: Immunization Recommendations

RECOMMENDED SCHEDULE FOR ACTIVE IMMUNIZATIONS OF NORMAL INFANTS AND CHILDREN

Recommended Age*	Vaccine(s)	Comments
2 mo	DTP-1, OPV-1	Can be given in earlier endemic areas
4 mo	DTP-2, OPV-2	6 week to 2 month interval desired between OPV doses
6 mo	DTP-3	An additional dose of OPV at this time is optional for use in areas with a high risk of polio exposure
15 mo**	MMR	Currently, a second immunization for one or more of these viruses is recommended. Check with state or local health department for current recommendations on re-immuniza tion
18 mo**	DTP-4, OPV-3	Completion of primary series
4-6 yrs##	DPT-5, OPV-4	Preferably at or before school entry. DPT may be given up to a child's seventh birthday. After that give DT only.
14-16 yrs	TD	Repeat every 10 years throughout life
	H-flu type b	Recommendations for Hemophilus b immunizations vary according to geographic location, risk factors and data on the protective efficiency of vaccine products. Check with your state or county health department for current, local recommendations.

Abbreviations

DPT Diphtheria and tetanus combined with pertussis vaccine
TD Adult tetanus toxoid and diphtheria toxoid in combination. Contains same dose of tetanus toxoid as DPT or DT and a reduced dose of diphtheria toxoid
OPV Oral attenuated polio virus vaccine (contains polio virus types 1, 2, and 3).
MMR Live measles, mumps, and rubella viruses in a combined vaccine
H-flu Hemophilus Influenza type B. This is a bacteria that can cause severe disease, especially in children under 5. This bacterium and its vaccine should not be confused with the influenza ("flu") virus and its vaccine that is sometimes recommended for at-risk adults.

* These recommended ages should not be construed as absolute, i.e., 2 months, can be 6-10 weeks, etc.

** Simultaneous administration of MMR, DTP and OPV is appropriate for patients whose compliance with medical care recommendations cannot be assured.

For all products used, consult manufacturer's package enclosure for instructions for storage, handling and administration. Vaccines prepared by different manufacturers may vary, and those of the same manufacturer may change from time to time. The package insert should be followed for a specific product.

RECOMMENDATIONS FOR ADULT IMMUNIZATION PRACTICE

The following recommendations apply generally to all healthy people.

Tetanus and Diphtheria Toxoids for Adult Use

All young adults should have completed a primary series of tetanus and diphtheria toxoids. People who have completed a primary series of tetanus and diphtheria immunization should receive a booster dose every 10 years.

Measles Vaccine

People born after 1956 should receive measles vaccine unless they have a dated record indicating they have been immunized with live measles vaccine on or after their first birthday; documentation of a physician's diagnosis of measles; or laboratory evidence of immunity, if available. People vaccinated for measles between 1963 and 1967 should be revaccinated.

Mumps Vaccine

Most adults are likely to have been infected naturally and generally may be considered to be immune, even if they did not have clinically apparent mumps. Mumps vaccine may be given, however, if there is concern about susceptibility.

Rubella Vaccine

Women of childbearing age should be assured of immunity against rubella. This vaccine should be given unless patients have proof of immunity by laboratory evidence or have received the rubella vaccine after their first birthday. Pregnant women should not be vaccinated.

Influenza Vaccine

Although influenza vaccine is not recommended for universal immunization of healthy adults less than 65 years of age, consideration may be given to immunizing such people who provide essential community services, including health care personnel who are at increased risk of exposure to or transmission of infection. This latter group includes some people with disability who may be susceptible to debilitating pneumonia.

Pneumococcal Vaccine

Pneumococcal vaccine is particularly recommended for people over 65 years of age. However, it may be considered for use in patients less than 65 based on individual physician judgment.

Hepatitis B Vaccine

Decisions on the administration of Hepatitis B vaccine should be based on risks of exposure. This varies from setting to setting. Check with your state or county health department for current, local recommendations.

VACCINATION DURING OR IMMEDIATELY PRIOR TO PREGNANCY

On the grounds of a theoretical risk to the developing fetus, live, attenuated-virus vaccines are not generally given to pregnant women or to those likely to become pregnant within 3 months after receiving vaccine(s).

Appendix B: Client Education for Identifying and Managing Minor Illnesses*

COMMON ILLNESSES: HOW TO IDENTIFY THEM AND WHEN TO CALL FOR HELP

An important task in facilitating health care for a child or an adult with a developmental disability, is being able to determine WHEN the person is sick and IF he or she needs to be evaluated by a health care provider. These may not be straightforward tasks. First of all, the decision is usually based on "second-hand" information; it's not your "ache", "pain", or "fever", but someone else's. Also the person may be unable to tell you that he or she does not feel well, or be unable to describe exactly what is wrong.

There are, however, general signs of illness; these signs usually involve a change. If you are alert to these, you can recognize many illnesses early in their course. Common changes are described in this section.

This section is meant to provide you with general guidelines for evaluating illness and for making decisions about when to call a physician or other health care provider. Consumer-oriented guides to health care, containing much more detailed information (several are listed in the resource list) are also available. While they do not give information that is specific to person with a developmental disability, they are very useful resources. However, these too, provide information that is only meant to be a guide. **If you are concerned and feel you need to talk to a health care provider, CALL—regardless of the information presented here or in any other resource. Similarly, when you call a health care provider, you may be told that the individual does not need to be seen. If you are still concerned, say so. If you want to be reassured by having a health professional evaluate the person, say so. Because you know the person, you are in the best position to notice changes. Respect your own judgment.**

CHANGES IN TEMPERATURE

The normal body temperature is 98.6 F orally (99.6 rectally, and 97.6 axillary—taken in the armpit), although there are individual variations. When a person's temperature rises more than a degree above normal, it is a fairly reliable sign of illness. Unless the person has had some sort of heat injury (i.e., sunburn, sunstroke, heat exhaustion) it usually means an infection. However, a higher-than-normal temperature is a general symptom that occurs with many different types of infection. It could be caused by a cold, a bladder infection, an abscessed tooth, or some other condition. Other symptoms need to be consid-

Call a physician or health clinic when

the person has an oral* temperature:

- Above 102° F
- Above 100° F with another obvious sign of illness
- Above 100° F for three or more days
- Below 95° F

or when they have an elevated temperature:

- Accompanied by a seizure or with a past history of seizures with elevated temperatures
- Accompanied by a stiff neck and headache, especially in children
- Accompanied by right-sided abdominal pain

*Adjust these temperatures by adding one degree if temperature is taken rectally; subtracting one degree if taken in the armpit.

* This section is taken from Pfaffinger and Nelson (1988). Quality health care for people with developmental disabilities. Minneapolis: Minnesota University Affiliated Program on Developmental Disabilities. (pp. 20-23).

ered in order to pin-point the source of the elevated temperature.

An elevated temperature should be treated by increasing the fluid intake in order to prevent dehydration. You may also want to give aspirin or acetaminophen (i.e., "Tylenol" or "Datril") if the person seems uncomfortable. However, children and adolescents should only be given acetaminophen. Do NOT give them aspirin. Aspirin use by children and adolescents has been associated with an increased risk of Reyes syndrome, a rare but serious illness

A BELOW normal temperature (95° F or below) can be the sign of a serious illness that needs prompt attention by a physician, especially in infants and young children.

CHANGES IN APPETITE

While fluctuations in appetite are common, a marked decrease in appetite may indicate illness. A decreased appetite may also be accompanied by nausea or vomiting. Children may simply complain vaguely of a "tummy ache". Even when individuals lose their appetites, it is important that they continue to take fluids. If the person has nausea and perhaps vomiting as well, small amounts of clear fluids (one to two ounces per hour) are often tolerated best.

Refusing to eat can be a serious problem for infants, since they rely on breast milk or formula not only for nutrition, but as their principal source of fluids. They can rapidly lose weight and become dehydrated.

Call a physician or health clinic when:

- A baby under six months of age stops eating, has difficulty eating (i.e., sucking or nursing) and/or doesn't seem to be gaining weight.
- A child who usually has a good appetite refuses food for a day and seems listless.
- An older child or an adult refuses food or has a significantly decreased appetite for two or more days.
- A child or an adult refuses (or is unable to keep down) FLUIDS as well as food for a day.
- A baby under six months of age has vomiting (NOTE: Infants frequently "spit up" small amounts after feeding. This is NOT considered vomiting.).
- A child or an adult has vomiting that lasts for more than 48 hours.
- A person has vomiting that is accompanied by dizzy spells and headaches or by right-sided abdominal pain.

CHANGES IN AFFECT OR BEHAVIOR

A change in affect (mood) or behavior can be sudden and dramatic, or it can be subtle and gradual. While such changes are sometimes difficult to judge, they can be early signs of illness. For instance, you should suspect illness when a child (or an adult) who is usually good-natured becomes crabby, when someone who is usually talkative becomes quiet and listless, or when someone who is fairly active starts acting tired or groggy. Analyzing these changes requires that you know the person's "normal" behavior and are alert to any differences.

Call a physician or health clinic when:

- Changes in affect or behavior are accompanied by other signs of illness
- You are concerned about changes in affect or behavior
- The person exhibiting changes in affect or behavior is taking medications

CHANGES IN APPEARANCE

Many of us have had the experience of just looking at someone and sensing that they are sick. Our hunch is most often based on the person's general appearance, especially his or her color. When someone is pale, flushed (red) or jaundiced (yellow), we sense that the person is not well, and we are often right. Rashes can also be a visible sign of illness.

Call a physician or health clinic when:

- The person is unusually pale.
- The skin or the "whites" of the eyes have a yellowish color (the person is jaundiced).
- Lips, fingernails or face are a bluish or purplish color (NOTE: This can be a sign of breathing or heart problems. If the person has this bluish color and is having difficulty breathing, call a physician IMMEDIATELY.).
- Skin is flushed WITHOUT recent exercise.
- A rash is accompanied by a fever.
- A rash is itchy, painful or spreading.
- The person has a rash and is taking a medication.

CHANGE IN BOWEL OR BLADDER HABITS

Some sort of change in bowel or bladder habits is a fairly reliable indication of illness. This could be an increase or a decrease in frequency. It could also be the loss of bladder or sphincter control for someone who previously had control.

Diarrhea is the frequent passage of loose, liquid stools. It is a sign of bowel irritation. It is frequently (though not always) caused by bacteria or viruses. This infection can be easily spread to others. Hand washing and careful handling or disposal of any soiled clothing or bedding is especially important when someone has diarrhea. Loose bowel movements can be normal for infants, but liquid or watery ones are not. Diarrhea in infants and young children can be serious, since it may lead to dehydration.

Constipation refers to bowel movements that are hard, dry and difficult to pass. It can frequently be treated without consulting a physician. Usually increases in fluid, fiber and activity are all that is required. Constipation, however, is another change that needs to be monitored.

Incontinence refers to the loss of bladder control in a child or an adult who typically has good bladder control. It can be the sign of a bladder infection. Increased urinary frequency may also be a sign of infection. On the other hand, a decrease in urinary frequency, or in the amount of urine being passed, can be a sign of dehydration.

Call a physician or health clinic when:

- An infant under 6 months of age has diarrhea (3 or more loose stools in a 24-hour period).
- A child or adult has diarrhea for more than 24 hours.
- The person has diarrhea accompanied by abdominal pain, fever or other obvious signs of illness.
- The person has a bowel movement that is bloody.
- The person voids only a small amount of urine that is dark yellow and strong smelling (i.e., concentrated).
- An infant or young child does not urinate for 4-6 hours.
- An older child or adult does not urinate for 10-12 hours or more.
- A child or adult has increased urinary frequency or complains of pain or a burning sensation when urinating.
- A child or adult who has had bowel or bladder control becomes incontinent.
- The person has constipation accompanied by abdominal pain.
- The person has constipation that does not respond to increased fluid, fiber and activity.

(NOTE: Constipation should NOT be treated with laxatives, suppositories or enemas without consulting a physician.)

CHANGES IN BREATHING

While people may have slight changes in breathing patterns with colds and fevers, rapid, noisy or difficult breathing usually signals problems that need prompt medical attention.

Call a physician or health clinic when:

- The person appears to have difficulty breathing
- Breathing appears more rapid or labored than normal
- Lips or fingertips have a bluish or purplish color

(NOTE: This may also occur when someone is cold. If the person is NOT having breathing difficulty AND normal color returns when he or she is warm, you do not need to call a physician.)

INITIATE RESUSCITATION AND CALL 911 OR YOUR LOCAL PARAMEDICS WHEN:

- The person's airway appears to be blocked.
- The person has stopped breathing.

EVALUATING COMPLAINTS OF PAIN

In addition to the above changes, which are general signs of illness, a person may have specific complaints, especially of pain. Pain includes a variety of symptoms—from a toothache, to a sore throat, to joint pain. All complaints of pain should be listened to and evaluated carefully. Some individuals have a high pain threshold, or an unusual tolerance for pain. There can be instances of broken bones or burns with no complaints of pain. This means you must be watchful for subtle changes and take what may seem like a minor complaint seriously.

Headaches can occur with stress, after a head injury, or with other symptoms such as sore throats or fevers. Headaches are fairly common in adults and as long as they are not frequent or severe, it is appropriate to treat them with over-the-counter medications such as aspirin and acetaminophen. On the other hand, headaches in young children are rare and generally need to be evaluated by a physician. Except for minor bumps, all head injuries should be evaluated by a physician.

Ear pain is often a symptom of an ear infection. It needs to be evaluated by a physician and frequently needs to be treated with an antibiotic.

A **sore throat** is a common complaint that frequently occurs with other cold symptoms such as a runny nose or a cough. It can be due to the same virus that caused the cold. There is no cure for viral illnesses such as the common cold, although increased fluid intake, throat lozenges, or salt water gargles may relive some of the throat pain associated with them. Some sore throats, on the other hand, are caused by the streptococcal bacteria (i.e., "strep throat"). This infection can and should be treated with antibiotic medications—both to relieve the symptoms and to prevent possible heart and kidney complications. Knowing the difference between a viral sore throat and a strep throat is not easy. A throat culture is needed for a positive diagnosis. If the person has a sore throat accompanied by a fever, swollen neck glands, enlarged and red tonsils, or white patches on the tonsils, you should contact a physician or health clinic so a throat culture can be done. Similar action should be taken if the person develops a sore throat after being exposed to someone with strep throat.

Tooth and jaw pain should always be evaluated by a dentist. Sores on the lips or in the mouth that do not heal within four or five days should, likewise, be evaluated by a dentist.

Stomach pains are fairly common in young children. They may be related to constipation, diarrhea, or sore muscles; or they may be the child's way of expressing stress. You should contact a physician if a child or adult has abdominal pain that is sharp; accompanied by nausea, vomiting or a fever; or persists more than two days.

Joint pains and muscle aches can occur with illness and fever or can be due to physical activity, especially if the activity is out of the ordinary for that individual. Consult a physician if the joint or muscle feels hot to the touch, if there is any swelling, or if there is a loss of movement in the joint or muscle because of the pain.

Appendix C: Selected Readings and Educational Materials

Information for full integration of people with developmental disabilities.

A new way of thinking. State of Minnesota, State Planning Agency. The Governor's Planning Council on Developmental Disabilities (1987).

A description of service trends and community integration for children and adults with developmental disabilities, including education, living and work settings.

Write: State Planning Agency
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155

complimentary copy

Purposeful integration....inherently equal. D. Biklen, S. Lehr, S. J. Searl, & S. J. Taylor. Syracuse, New York: Syracuse University, the Center for Human Policy (1987).

This manual defines the concept of integration and discusses its importance. It describes model programs and presents strategies which can be used to facilitate integration.

Write: Federation for Children with Special Needs
312 Stuart Street, 2nd Floor
Boston, MA 02116
617-482-2915

$5.00 per copy

Health service standards and guidelines

The lifetime health monitoring program: A practical approach to preventive medicine. Lester Breslow and Anne Sommers. New England Journal of Medicine (March 17, 1977), 299:11, pp. 601-608.

This article proposes health goals for each age group, and suggests preventive services that should be responsive to these goals. A detailed list of services is provided for infants and older adults.

Standards of child health care (3rd ed.). American Academy of Pediatrics (1977).

This publication includes chapters on preventive health care, care during illness, office equipment and facilities, medical records, community responsibilities of pediatricians and other topics related to pediatric practice. The intent is to offer guidelines rather than propose rigid criteria. NOTE: Copies of this publications are no longer available for purchase. A revised edition is anticipated, but until that time, this document reflects current standards.

Standards for obstetric-gynecological services (6th ed.). American College of Obstetricians and Gynecologists (1985).

Recommendations for agencies, hospitals and individual practitioners providing obstetric and gynecological health care. Contains recommendations for ambulatory care and risk-factor assessment.

Write: American College of
Obstetrics and Gynecology
Distribution Center
600 Maryland Avenue, SW
Washington, D.C. 20024-2588

$25.00 per copy

Standards for the obstetric, gynecologic and neonatal nursing (3rd ed.). Nurses' Association of the American College of Obstetricians and Gynecologists (1986).

Describes concepts and procedures of perinatal and gynecological nursing practice.

Write: NAACOG Publications
600 Maryland Avenue, SW
Suite 300 East
Washington, D.C. 20024-2588

$10.00 per copy

Chronic Health Problems and Disabilities

Quality health care for people with developmental disabilities: A guide for parents and other caregivers. K. Pfaffinger & R. P. Nelson. Minnesota University Affiliated Program on Developmental Disabilities (1988). A consumer's guide to health delivery systems, health care standards, illness management and health promotion practices with a focus on special considerations for people with developmental disabilities.

Write: Institute on Community
Integration
University of Minnesota
109 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
(612) 624-4512

$5.00 per copy

The chronically ill child: A guide for parents and professionals. A. T. McCollum. New Haven, CT: Yale University Press (1981).

A guide to understanding and caring for the child with a chronic illness.

Guidelines for families: Improving health care for children with chronic conditions. Alfred Healy and J. Arline Lewis-Beck. Iowa University Affiliated Program (1987).

These guidelines were developed by parents of children with chronic conditions. It consists of lists of practical recommendations on identifying health problems, determining needs and services, participating in care, and advocacy.

Write: University of Iowa
Campus Stores
208 G.S.B.
Iowa City, IA 52242

$2.50 per copy

Family-centered care for children with special health care needs (2nd Ed.). T. L. Shelton, E. S. Jeppson, & B. H. Johnson. Association for the Care of Children's Health (1987).

A guide for health professionals that lists barriers to family participation and clear, practical suggestions to overcome these.

Write: Association for the Care of Children's Health
3615 Wisconsin Ave North
Washington, D.C. 20016

$5.00 per copy plus postage

Community health care services for adults with mental retardation. *Mental Retardation*, 25(4) (1987, August).

Entire issue reviews symposium proceedings on health services for adults with mental retardation. Includes articles on health care needs, report of model programs, public financing of health services, and dental health care for adults with mental retardation.

Reproductive Health and Sexuality

Sex education for individuals with developmental disabilities: An annotated bibliography. B. McKray, R. Chambers, and K. Green, et al., University of Iowa, Division of Developmental Disabilities (1982).

Consists of a subject listing, an annotated bibliography, and two appendices for educators, parents, health professionals and people with handicaps. Subjects include adolescents, contraception, genetic counseling, sex education programs and sexually transmitted diseases. Both print and audiovisual materials are reviewed.

Write: University of Iowa
Campus Stores, Room 30
Iowa Memorial Union
Iowa City, IA 52242
319-454-2121

$5.00 per copy plus postage

A *guide for teaching human sexuality to the mentally handicapped (4th Ed.)*. Planned Parenthood of Minnesota (1977).

This guide addresses educational content on anatomy, menstruation, intercourse, conception, pregnancy and birth, contraception, relationships, masturbation, rape and venereal disease. Also contains lists of resource materials on each topic.

Write: Planned Parenthood of Minnesota
1965 Ford Parkway
St. Paul, MN 55116
612-698-2401

$3.50 per copy

A selected bibliography on sexuality, sex education and family planning for use in mental retardation programs. Planned Parenthood of Minnesota (1985).

The materials listed are for professional education and training, parent education and client education in the areas of reproductive health, birth control, sterilization and general concerns. Although not all resources listed were designed specifically for people with mental retardation, they can be easily adapted for this audience.

Write: Planned Parenthood of Minnesota
1965 Ford Parkway
St. Paul, MN 55116
612-698-2401

$3.50 per copy

When parents consider sterilization for their sons or daughters who are mentally retarded. Association for Retarded Citizens of Minnesota (1984).

This paper provides basic information and legal implications when sterilization is considered for individuals who have mental retardation. It also outlines the questions that should be carefully thought out when sterilization is considered.

Write: Association for Retarded Citizens of Minnesota
3225 Lyndale Avenue South
Minneapolis, MN 55408
612-827-5641

Dental Health

A manual of oral hygiene for handicapped, aged and chronically ill patients. Marathon County Health Department (1983).

A basic reference or staff members providing care in residential facilities that addresses dental health, dental hygiene, toothbrush adaptations for people with physical impairments, cleaning and maintaining dentures, and additional resources.

Write: Dental Hygienist, Marathon County Dental Health Project
Marathon County Health Department
400 East Thomas Street
Wausau, WI
715-848-1406 or
1-800-472-0082

Recommended infection-control practices for dentistry. The Centers for Disease Control. *Morbidity and Mortality Weekly Report*, 35(15) (1986, April 18).

Reviews recommended infection control practices for dental personnel in the routine care of all patients. Topics include use of protective attire, handwashing and hand-care procedures, use and care of ultrasonic scalers, handpieces and dental units, handling of biopsy specimens and disposal of waste materials.

Suggested schedule for preventive child dental care. American Academy of Pedodontics, American Association of Orthodontists, and American Academy of Pediatrics. *Pediatric Clinics of North America*, 29, 653.

Outlines a schedule for child dental care from newborn to 19 years of age. Identifies developmental landmarks and lists appropriate procedures.

Dental management for persons in the community. Massachusetts Department of Public Health (1985).

This manual is designed to offer the dentist basic information about current concepts in the dental management of people with developmental disabilities including definitions and descriptions of categories of disabilities, attitude of professionals, case-finding and referral, office accessibility and the role of dental hygienist in the care of individuals with developmental disabilities.

Write: Massachusetts Department of Public Health
Division of Dental Health
150 Tremont Street, Room 8M
Boston, MA 02111
(617) 727-0732

Dentistry for the handicapped patient. A. J. Nowak. St. Louis: Mosby (1976).

Covers basic information on various disabilities, topics on preventive management and suggestions for providing dental care for people with disabilities.

Nutrition

Nutrition for children with special needs: For parents, teachers, aides, volunteers and the health care professional. United Cerebral Palsy of Minnesota, Inc. (1985).

Provides information on specific nutrition problems related to handicapping conditions and on feeding skill development and texture foods. Provides list of resources and offers teachers ideas for nutrition education in special children.

Write: United Cerebral Palsy of Minnesota, Inc.
233 South Griggs Midway Building
1821 University Avenue
St. Paul, MN 55104
(612) 646-7588

$6.00 per copy for professionals
$3.00 per copy for parents

Exercise

An introduction to fitness with people who are disabled. Christopher Roland and Larry Partridge (Eds.). Loretto, MN: Vinland National Center.

A manual designed to encourage people with disabilities, as well as health care, recreation, and educational professionals, to implement or expand fitness training programs. Information is presented on principles of exercise and various fitness activities. Basic techniques for fitness activities are outlined and specific activities are suggested for specific disabilities.

Write: Vinland National Center
P.O. Box 308
Loretto, MN 55357

Community recreation and people with disabilities. Stuart J. Schleien and M. Tipton Ray. Baltimore, MD: Paul H. Brookes Publishing Co. (1987).

Discusses strategies to integrate the person with disabilities into community recreation programs including ways to overcome obstacles to participation, solutions to typical problems and procedures for program evaluation. Also contains an annotated bibliography on current and relevant literature.

IMPACT: Feature issue on integrated education. S. Schleien & V. Rynders, (Eds.). Minneapolis, MN: Institute on Community Integration (1989).

This newsletter presents a number of articles related to integrated community-based recreation/leisure activities for persons with developmental disabilities. Topics include recreational preferences of individuals with disabilities, criteria for program evaluation, and profiles of outstanding programs.

Write: Institute on Community Integration
109 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
(612) 624-4512

Integrated Education

IMPACT: Feature issue on integrated education. J. York & T. Vandercook, (Eds.). Minneapolis, MN: Institute on Community Integration (1988).

This newsletter presents a number of articles related to integrated education. Topics include district level strategies, individual student strategies, individual educational goals and objectives, parent perspectives, and the changing role of special education.

Write: Institute on Community Integration
109 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
(612) 624-4512

$1.00 per copy

Preparing for life: A manual for parents on least restrictive environment (Vol. II,. Questions and answers.) Technical Assistance for Parent Programs (TAPP) Project. Boston: Author (n.d.).

This manual, written in easy to understand language, provides answers to a number of questions which are frequently asked about integrated education.

Write: TAPP Project
312 Stuart Street, 2nd Floor
Boston, MA 02116
(617) 489-2915

Regular Lives (videotape). T. Godwin & G. Wurzburg (Producers). Washington, DC: State of the Art Productions (1988).

This documentary focuses on individuals with disabilities who are successfully integrated in typical school, work and living environments. The perspectives of individuals with and without disabilities, parents of children with and without labels, special and regular educators, employers, and a school principal are presented.

Write: WETA, Educational Activities
Box 2626
Washington, D.C. 20013
(800) 445-1964

$34.95 per copy

Appendix D: Community Resources

Organizations

Alternatives for People with Autism
5624 73rd Avenue North
Brooklyn Park, MN 55429
612-560-5330

Association for Retarded Citizens Minnesota (ARC)
3225 Lyndale Avenue South
Minneapolis, MN 55408
612-827-5641
MN toll free 1-800-582-5257

Community Health Education Network (CHEN)
3225 Lyndale Avenue South
Minneapolis, MN 55408
612-827-5641
MN toll free 1-800-582-5257
(Provides information on health and obtaining health care services for people with mental retardation to parents and direct service providers. Also maintains a lending library.)

Epilepsy Foundation of Minnesota
672 Transfer Road
St. Paul, MN 55114
612-646-8675
MN toll free 1-800-292-7932

Legal Advocacy for Persons with Developmental Disabilities
222 Grain Exchange Building
322 Fourth Avenue South
Minneapolis, MN 55415
612-338-0968
MN toll free 1-800-292-4150

Minnesota Association for Persons with Severe Handicaps
PO Box 1837
Pioneer Station
St. Paul, MN 55101

University of Minnesota Institute on Community Integration
6 Pattee Hall
150 Pillsbury Drive SE
Minneapolis, MN 55455
612-624-4848
(Training, technical assistance and continuing education for personnel working with individuals who have severe and profound developmental disabilities.)

National Center for Youth with Disabilities, Adolescent Health Program
University of Minnesota
Box 721
Hospital and Clinics
Harvard Street at East River Road
Minneapolis, MN 55455
612-626-2825
(Technical assistance and computer-based resource library for professionals and agencies serving adolescents with chronic illness and/or disability.)

Parent's Advocacy Coalition for Educational Rights (PACER)
4826 Chicago Avenue
Minneapolis, MN 55417
612-827-2966

Twin City Society for Children & Adults with Autism, Inc. (TCSAC)
253 East Fourth Street
St. Paul, MN 55101
612-228-9074

United Cerebral Palsy of Minnesota
233 South Griggs Midway Building
1821 University Avenue
St. Paul, MN 55104
612-646-7588

Public Programs

Governor's Planning Council on Developmental Disabilities
Minnesota State Planning Agency
300 Centennial Office Building
658 Cedar Street
St. Paul, MN 55155
612-0296-4018
612-296-9962 (TTY)

County Public Health Nursing Agencies
For information, contact your local county offices, or Section of Public Health Nursing
Minnesota Department of Health
717 Delaware Street SE
Minneapolis, MN 55440
612-623-5468

Medical Assistance Program
For information, contact your local county human services office, or Minnesota Department of Human Services
444 Lafayette Road
St. Paul, MN 55155
612-296-3386
MN toll free 1-800-652-9747

Minnesota Department of Human Services
Division for Persons with Developmental Disabilities
444 Lafayette Road
2nd Floor
St. Paul, MN 55155
612-296-2160
(Monitors community-based services and approves medical assistance support for people with mental retardation and related conditions.)

Minnesota State Council on Disability
208 Metro Square Building
Seventh and Robert Street
St. Paul, MN 55101
612-296-6785 (voice or TTY)
MN toll free 1-800-652-9747

Service Resources

Children's Hospital of St. Paul
345 North Smith Avenue
St. Paul, MN 55102
612-298-8888

Comprehensive Epilepsy Program
2701 University Avenue SE
Minneapolis, MN 55102
612-331-4477

Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422
612-588-0811
(Rehabilitation and independent living services for children and adults with disabilities.)

Gillette Children's Hospital
200 University Avenue East
St. Paul, MN 55104
612-291-2848
(Health care center for children and adults with disabilities.)

Minneapolis Children's Medical Center
2525 Chicago Avenue South
Minneapolis, MN 55404
612-863-6100

Polinsky Medical Rehabilitation Center
Pediatric Services
530 East Second Street
Duluth, MN 55805
218-727-5052

St. Paul Rehabilitation Center
319 Eagle Street
St. Paul, MN 55102
612-227-8471

Shriner's Hospital for Crippled Children
2025 East River Road
Minneapolis, MN 55414
612-339-6711

University of Minnesota Rehabilitation Center
420 Delaware Street SE
Minneapolis, MN 55455
612-626-3696
MN toll free 1-800-462-5301

Vinland National Center
P.O. Box 308
Loretto, MN 55357
612-479-3555
(Healthsports, health promotion and life-enhancement activities for individuals of varying ability.)

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